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ABSTRACT

This issue examines the causes and effects of stress among parents of handicapped children and offers guidance for reducing and/or avoiding stress. The factors contributing to parental stress are identified, including unfounded guilt feelings, prolonged dependency of the handicapped child, extended care requirements, marital discord and family tensions, increased financial burdens, and reduced free time. The typical physical, emotional, and behavioral responses to stress are then enumerated. Suggestions provided for reducing stress include relaxing through exercise or other diversion, learning yoga or other meditation techniques, using biofeedback, attending to one's own needs for short periods of respite, using guided imagery, and immersing oneself in a hobby or pastime. Methods of avoiding stress which require longterm changes in attitudes or habits are presented through discussions of such issues as acceptance, communication, and time management. A list of parental "do's" and "don'ts" is provided along with a psychologist's suggestions for easing feelings of guilt: (1) accept that the past cannot be changed; (2) promote self-approval; (3) examine effects of one's behavior on oneself and others; and (4) do not let others use guilt as a weapon. (VW)

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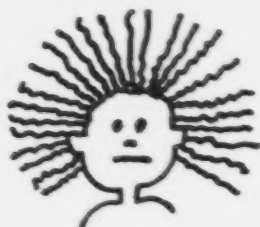
Special Parent ★ Special Child★

Practical pointers for parenting handicapped children

VOL. 3, NO. 6

NOVEMBER/DECEMBER 1987

DEALING WITH STRESS



Now that the holiday season is here and there is even less spare time, special parents more than others seem prone to stress. We hear from our readers that "other people don't have the problems we have—they seem happier, they are able to enjoy the hustle and bustle of Thanksgiving and family gatherings and gift giving. Planning holiday events around my child's disability takes so much effort that there's little left for holiday spirit."

Expecting to be happy around the holidays and assuming that everybody except you is content are **mistaken beliefs** that unfortunately add to the stress level of the special parent.

In this issue we will examine the unique circumstances that make the special parent vulnerable to stress, how to recognize the symptoms of stress and specific ways to reduce and avoid this enervating condition.

The special parent is vulnerable

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Often parents of special children do not recognize that the circumstances and constraints of caring for their special child place them immediately in a high stress category.

Stress and expectations. All parents have certain expectations for their children which, in the case of the special child, often remain unfulfilled. This may worsen as the child gets older and the disability remains unchanged. "He will get better, won't he?" and "he's going to outgrow the problem" are dreams and hopes that when dashed can cause

stress. Often, unfounded guilt feelings of having done something wrong increase stress even more.

The special child's dependency is often prolonged and his ability in learning how to walk, talk, self-feed or toilet is delayed. This increases the special parents' responsibilities which often adds to stress.

The need for 24-hour-a-day care poses an additional problem, for even though the special parent devotes much time and attention, his disabled child's ability to respond might be so limited that the parent receives little reward for his efforts.

Many special children are susceptible to illnesses or infections requiring extra care. Parents who are frequently exhausted or, because of circumstances, are denied the intrinsic rewards of parenting are vulnerable to stress.

Marital discord and family tensions can arise, especially if spouses disagree with each other on how to handle their disabled child.

Increased financial burdens often plague the special parent. Medical insurance frequently does not fully cover the cost of medicine, doctors, specialized equipment or clothing. Babysitters and recreation programs are often more costly.

The toll on free time affects the entire family. Parents often have to use up precious vacation days on doctor's visits, hospital tests and school conferences for their disabled youngster. Finding time to meet the needs of siblings or

even to cope with the normal, everyday growing-up problems of their other children is often difficult.

Even the day-to-day activities that other parents accomplish with regularity and ease—finding a babysitter, the right doctor, a decent school or after-school programs—create time-consuming hassles when the child has special needs.

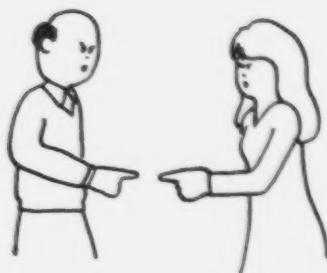
As one special parent commented, "It's not the major things that wear me down. It's the minor irritations like always having to be there to meet my special child's school bus long past the age other kids are on their own or having to plan ahead just to go food shopping by myself." When these and other concerns are added to the frustrations faced by special parents, precious reserves of energy are sapped and stress takes over.

ABOUT THE AUTHORS

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Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

Recognizing stress



Stress is the physical, emotional and behavioral response to change. Glad tidings as well as bad can produce feelings of stress. A new job, a new house, changes in finances either up or down, death or illness of a loved one—any changes, even minor ones, can trigger stress responses. Stress is the way our bodies and minds react to events that threaten our equilibrium. It becomes especially evident when we feel we cannot exercise control.

Physical stress responses include:

- tightness in chest
- increased blood pressure
- tics
- skin rashes
- neck pain
- change in appetite
- night sweats
- muscle tightness or spasms
- sleep disturbances
- fatigue
- prickly or tingling skin sensations
- stomach upsets
- backaches.

ABOUT SPECIAL PARENT/SPECIAL CHILD:

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Many doctors believe that over half of our physical ailments are stress-related. When faced with stressful circumstances, our bodies' auto-immune system loses some of its ability to fight off illness. Hence, feeling stressed can cause or worsen many diseases.

The emotional responses to stress are:

- withdrawal from friends, family
 - distractibility, difficulty concentrating
 - mood swings
 - restlessness
 - frantic activity or lethargy
 - crying jags, jittery nerves

- depression
- anger flare-ups.

Some behaviors that can arise include:

- nailbiting
- hair twisting
- increased smoking, alcohol consumption, drug use
- compulsive eating, food binging or refusal to eat
- compulsive neatness or letting things pile up.

If any of these responses is prolonged or intense, the special parent should seek professional help.

Reducing stress



Although there are long-term strategies that can help in avoiding stress, once you recognize that you are suffering from stress, the immediate goal is to **reduce** the damaging symptoms as quickly as possible.

Relaxation is the key to stress reduction. Some people opt for strenuous exercise as a way of relieving tensions; others find a hot bath or a good book more to their liking. Here are some short-term effective remedies for reducing stress:

- running, jogging or walking briskly for two miles
- bicycling
- swimming laps
- aerobics or exercise class or working out
- dancing or jazz exercise
- endurance sports, such as cross-country skiing

Exercise is a known antidote to stress because sustained physical exertion is associated with the release of certain brain chemicals that act as natural tranquilizers. People who exercise on a regular basis tend to feel better, sleep better and have more energy.

Taking up either yoga, meditation, deep breathing or Tai Chai (an ancient Chinese form of dance and meditation) can be beneficial. These and other similar activities not only relax and rejuvenate, they become a source of satisfaction as the participant moves from one level of skill to the next.

Biofeedback is another specific stress reduction technique where trained specialists, using sensitive measuring instruments, teach you how to become aware of subtle physical changes in your body. Once you have learned how to control such things as muscle tension or skin temperature, for example, it becomes easier for you to relax.

Be good to yourself. Many special parents are either so busy or involved with the demanding role of caretaker that they neglect to take care of their own needs and wants. Overtaxed special parents find themselves vulnerable to stress responses which interferes even more with their ability to care for their disabled child. In order to break

the cycle of fatigue-stress-fatigue, it is essential to take advantage of ways that will not only offer respite but provide justly deserved enjoyment. These needn't be costly or elaborate, for example:

- take a walk, alone if you wish
- find time for a hot bath, whirlpool or sauna
- rent a video you've always wanted to see (you can even rent the VCR if you don't have one)
- go shopping for yourself
- go window shopping
- plan a romantic dinner at home with your spouse—after the children are in bed
- treat yourself to a long phone conversation with a close friend or relative, someone to whom you can ventilate your feelings
- try a new hairstyle, makeup or facial
- get a massage
- go to a Sunday brunch and leave all the children with a sitter or a relative. Short respite periods are often easier to arrange.

Guided imagery is another method that special parents might find useful because it doesn't require sophisticated equipment or formal classes. Find a quiet place to sit down, close your eyes and

imagine a place you find especially soothing—a warm, sunny beach or perhaps a flower-filled meadow. In your mind's eye, take yourself to this favorite spot and recreate the sounds, smells, the feel of the warm sun, the scent of the wildflowers. Try to "stay" in your soothing spot for 15 or 20 minutes. This is also a helpful method to get to sleep if you are restless at night.

Immerse yourself in a hobby or pastime. Activities that require your concentration or that are completely engrossing are by their very nature effective ways of reducing stress. Try one or more of the following or make up your own favorites:

- computers, computer games
- chess, bridge, cards
- ceramics, weaving, crafts
- painting or drawing
- cooking, baking, kneading bread
- sewing, needlepoint, macrame
- music

These activities have measurable outcomes or finished products or allow you to set a goal and chart your progress—all good ways of raising self-esteem along with reducing stress.

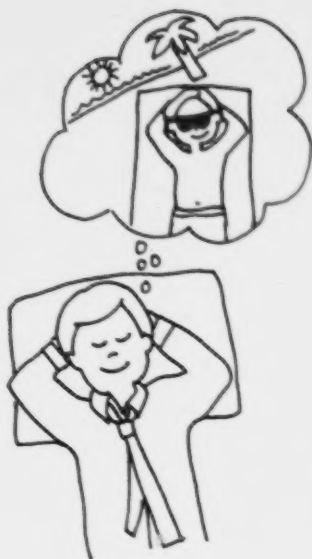
Avoiding stress

Although short-term strategies for reducing stress can be effective for a time, in the long run it's best to find ways that will help prevent or avoid stress entirely. As this often requires a change in attitude or habits, it is much more difficult but well worth it.

Acceptance. Accepting what has occurred in your life, although not easy, is a must if you want to avoid stress. You cannot go on with your life, maximizing your own and your special child's

potential, if you waste precious energy denying things are wrong or blaming others—doctors, schools, clinics. Both denial and belligerent anger are self-destructive states that will cause not only sadness and depression, but will ultimately paralyze your effectiveness as a special parent.

This does not minimize the painful fact that your child is disabled nor discount that having a special child is hard to bear. Recognize that feeling sad is a



SOURCES OF HELP

Family Services of America
11700 West Lake Park Drive
Park Place
Milwaukee, WI 53224
(414) 359-2111

American Association of Marriage
and Family Therapy
1717 K Street NW, Suite 407
Washington, DC 20006
(202) 429-1825

"Rapid Relief for Emotional Distress"
by Gary Emery, Ph. D., & James Campbell,
M.D.
Rawson Associates, 1986

normal reaction and then go on from there.

One of the best ways to achieve acceptance is to find out everything you can about your child's handicapping condition. Becoming knowledgeable will give you a sense of competency, especially if you know what to expect. Seek professional advice on how best to deal with your special child's needs.

Becoming part of the parent-teacher-professional team will give you a sense of being on top of the situation. Find a parent support group, especially one where parents have children with similar disabilities. Finding ways of dealing with child-rearing problems specific to your own child's can be life saving. It's comforting to know, too, that other parents feel cheated, hurt and angry and perhaps have found ways to overcome such feelings. Sharing ideas and feelings with other special parents who empathize with you can be therapeutic.

One of the keys to achieving acceptance is to stop focusing on what is wrong with your lot in life. Make a concerted effort to discover some aspect about each day that is good. As trite as this may seem, developing your power of positive thinking will go a long way toward accepting things that cannot be changed.

Learn to communicate. Your survival as a special parent depends on your ability to communicate. Ignoring your frustration or letting your anger build up instead of sharing your feelings and ideas leads only to depression and hostility.

Expressing your genuine feelings and losing your temper are two different things, however. Blaming others, shouting, pouting or screaming is misdirected and

nonproductive. It doesn't change the situation that created the anger and it turns off the people who might have been willing to help if the problem had been stated clearly from the outset.

Be honest with yourself, examine just what it is that is bothering you and then learn to confront others, even if what you have to say is unpleasant. It is possible to let others know precisely what is wrong without succumbing to rage or sarcasm. Be specific about what is troubling you without dredging up the past as this doesn't help either.

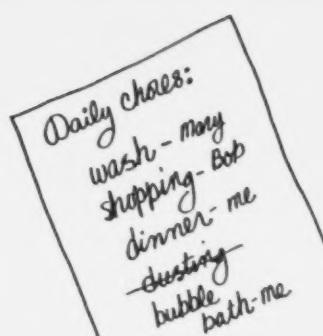
In order to communicate effectively, it is vital to learn how to listen. Many marital disagreements and family tensions can be avoided if you take the time to listen carefully to what the other person is saying. Don't interrupt or form phrases in your mind while the other person is trying to talk to you. Communication is a two-way street; giving your undivided attention will enable you to find out what others are really thinking, will prevent misconceptions and will enhance relationships. This in itself helps avoid stress.

Managing time. Managing time is quite different from having an inflexible schedule. Managing time means **prioritizing** or choosing what things are important and deserve your immediate attention and what things can wait until tomorrow.

Start by making a list of things that you either want done or need to be done. This could include doctors' appointments, housecleaning chores, social events, job commitments.

Decide which things on the list take priority. Part of the problem of feeling rushed, overtaxed and stressed is that the low priority





items on your list are being included when they shouldn't be. First divide the list in two. List those things that **must** be done in order of their importance. On the second half, list those things that must be done on a daily basis, in order of their importance.

Ask yourself:

- can anything be eliminated?
- what items can be delegated to others?
- can anything be done at a

later date? Be specific about this so that you don't feel guilty that you are sloughing off.

Be sure to include at least one activity on your daily list that's there because it makes you feel good. Even making sure you have allotted time for a relaxing hot bath every day is a good way to start.

Knowing that you are managing time and that time is not managing you will avoid feelings of helplessness and stress.

Do's and don'ts

- **Do recognize your feelings for what they are.** Repressing reactions of hurt and frustration will not point you in the direction of finding support or help.

- **Do become actively involved in planning for your special child.** Participating with professionals and making sure your ideas are given due consideration will give you a sense of being in control.

- **Do find a confidante** with whom you can share your feelings freely. More than likely another special parent who can understand your day-to-day concerns is the best choice.

- **Don't get in the habit of being** evasive or pretending everything's fine; this will only build up tension.

- **Do seek professional help** if you find yourself increasingly overwhelmed, powerless and immobilized. Your family doctor is a good resource; he or she can refer you to social workers, parent counselors or other clinicians. Make sure that they are experienced in the problems of parenting a special child.

- **Don't be guarded** with the person you have selected to help you. You have to be able to work

openly and honestly with professionals. If after a time, however, you feel uncomfortable or determine that the relationship is not beneficial, don't hesitate to find someone else more aware of your needs.

- **Don't make unrealistic demands or create rigid schedules** of when, what and how things should be done. The special parent dwells in the realm of the unexpected so it's best if you keep things simple. No one will think the worse of you if you dispense with polishing the silver and crystal, for example. It's better to relax and enjoy family and friends with picnics or pot-luck suppers, for instance, where everyone contributes.

- **Don't go it alone or isolate yourself from others.** Maintaining close family ties or a warm rela-



FROM THE EDITORS

We would love to hear your suggestions or hints on relaxing or reducing stress. Write to us at Lindell Press, P. O. Box 462, South Salem, NY 10590

tionship with a caring friend or an affiliation with a church or religious organization can be a source of comfort and support.

• **Do remember that parents** of special children feel guilt-ridden, especially when it comes to taking time for themselves. Although this is natural, it is self-destructive. Time away or time spent on yourself enables you to return to the challenge of raising a special child with a refreshed outlook and renewed love.



Psychologist's corner: EASING GUILT

by George Popper, Ph. D.

One of the more interesting qualities humans possess is the ability to express a wide variety of emotions. Other creatures also experience "feelings"—cat or dog owners can tell you when their pet is feeling content, frightened or aroused—but these are really primitive emotions intended to send clear signals to other creatures and help the animal survive. At one time, human expression served a similar purpose and, to a large extent, we still rely heavily on such things as body language and other non-verbal cues for much of our communication.

As humans became more civilized, some of the ways in which we expressed our feelings became vague and ambiguous. People developed emotions that are uniquely human—worry and guilt. Dr. Wayne Dyer, in his book "Your Erroneous Zones," said, "If you believe that feeling bad or worrying long enough will change a past or future event, then you're residing on another planet with a different reality system." While many emotions serve a useful, necessary purpose, worry and guilt do little more than create unnecessary pain and confusion,

especially to the special parent.

Feeling guilty seems to be an important part of our culture and is taught to us from early childhood. How many parents have used guilt as a way of disciplining their children? We quickly learn that one of the most effective ways of punishing someone is to make him feel just as guilty as we can. What really happens, however, is that we use our own emotions to punish ourselves.

Let's take a critical look at this thing we call guilt. Most often, it refers to something that has happened in the past. It refers to something we "should" have done or "should not" have done in a way that implies that somehow we can jump in a time machine and magically change what is out of our hands.

Most people are willing to agree, at least on an intellectual level, that the past is past and that no matter how badly you feel or how badly you want to alter yesterday, it can't be done. So why do we consciously punish ourselves with guilt over something that is truly impossible

for us to change? For one thing, it allows others to pat us on the back and tell us we're really not as bad as we think we are and that we are deserving of their pity. Perhaps in some way feeling guilty allows us to shift the responsibility of what has happened to someone or something else.

Whether we're seeking approval, pity or anything else, it doesn't alter the fact that nothing has really changed. What is important for all of us to understand is that guilt is ultimately self-defeating and that we would be able to live happier, more productive lives without it. But how can we rid ourselves of something that is so much a part of who and what we are? Is it something that is humanly possible to do? The answer is "yes," however, it takes hard work and coming to terms with what you are doing.

Here are some suggestions you might find helpful in dealing with this problem. Be aware that special parents more than others assume responsibility for events beyond their control.

1. First, accept that the past cannot be changed no matter what. Think about changing some of the ways you talk about the past. For example, try not to use the word "should." When we say

we "should have done this" or "should not have done that" we are talking in terms of absolutes. We imply that we have a crystal ball somewhere and can look into the future with perfect accuracy. What we really mean to say is that if we knew yesterday what we know today, then our behavior might well have been different. Instead of saying "I should have done this," it would be better and much less destructive if you say "if I knew then what I know now, it **would** (not "should") have been better had I done things differently." So face the fact that you don't own a crystal ball or a time machine and that your ability to make decisions and choices is based mostly on the information that was made available to you at the time those choices and decisions were made. If you've made a mistake, it's usually because you weren't able to fully determine all possible outcomes or because you just didn't have all the facts.

2. Most of us want others to like us. There are going to be times when despite our best efforts we will anger or lose the approval of someone who is important to us. We must remember that self-approval is more important than the approval of others.

3. Take a better look at the consequences of what you do. Use your ability to reason and think to help you take a more honest look at the effects of your behavior on others and especially on yourself.

4. Don't let others use guilt as a weapon to control or to influence you. Make them aware that you know what they are trying to do and that their attempts to manipulate you in this fashion won't succeed.



Coming next issue:
PARENT-TEACHER RELATIONSHIPS